PULMONARY HYPERTENSION

MariposaNews

n. 3 · Winter 2010

WINTER ISSUE OF THE NEWSLETTER OF PHA EUROPE, EUROPEAN PULMONARY HYPERTENSION ASSOCIATION

Austria
Belgium
Bulgaria
Czech Republic
France
Germany
Greece
Hungary
Israel
Italy
Netherlands
Norway
Poland
Portugal
Slovakia
Spain
Sweden
Switzerland
Turkey

European patient leaders from18 countries attended PHA Europe's Annual General Assembly 2010: Austria, Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Ireland, Israel, Italy, Netherlands, Norway, Poland, Slovakia, Spain, Sweden, Switzerland, Turkey.

● Activities of PH patient associations in Europe and around the world ● PHA Europe at the European Society of Cardiology Congress in Stockholm ● European PH leaders meet in Barcelona for the Annual General Assembly of PHA Europe ● ESC Educational Course on PH in Sophia Antipolis ● Update on PH treatments and research on PH drugs ● Monitoring developments in the European Institutions and NGO's ● Upcoming events for 2011 ● Interesting links and reading suggestions ●

PHA EUROPE

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Editors Memo

Dear friends,

I am delighted to introduce the Winter issue of PHA Europe's official journal, MARIPOSA NEWS. You will note that we have made a few changes to the graphic lay out. First of all, as suggested by some of the members, we have added the word "Pulmonary Hypertension" just above "Mariposa News" in order to emphasize the contents of newsletter. Secondly, it was felt that the covers of the Spring and Summer editions looked too similar and this needed to be changed and so we decided to add a photo. However, after having added the photo, there was no longer any room for the Editor's memo or Table of contents, so these have now been moved to page 2. Another novelty is the map of Europe highlighting PHA Europe membership (see above). Finally, the page with general information about the disease is now at the end of the journal.

Once again I would like to thank the national patient associations for sharing their achievements and providing precious input for the first sections of Mariposa. All have been very busy in their respective countries, witness the impressive number of patient meetings, publications, campaigns and other events organized in the last few months.

This edition contains reports of both the EUROPEAN SOCIETY OF CARDIOLOGY (ESC) and EUROPEAN RESPIRATORY SOCIETY'S (ERS) Annual Congresses. The ESC Congress was held in Stockholm from the 28th August to the 1st of September. PHA Europe was present as exibitor and was represented by Pisana Ferrari (PHA Europe Vice President) and Luisa Bonelli (PHA Europe Secretary), both from Italy. The ERS Congress was held in Barcelona from the 18th to the 22nd of September and on this occasion PHA Europe held its 2010 ANNUAL GENERAL ASSEMBLY in addition to being present at the ERS exibition. We are very gratified by the exceptional turnout: 37 delegates from 18 European countries: Austria, Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Israel, Italy, Netherlands, Norway, Poland, Slovakia, Spain, Sweden, Switzerland, Turkey. Our members from Greece and Portugal were unable to attend and were greatly missed. The General Assembly had a very wide ranging programme with interactive sessions between members about issues of common interest and presentations from distinguished speakers from the medical world. PHA Europe also held its first meeting with representatives of the pharmaceutical industry.

Another important event was the recent ESC EDUCATIONAL-COURSE ON PULMONARY HYPERTENSION held in Sophia Antipolis, France, from the 16th to the 17th of October, where I was asked to speak about "Patient Expectations" within the context of the ANNUAL G5. This meeting brings together all stakeholders involved in PH patient care: physicians, nurses, industry, regulatory authorities and patients.

The last part of MARIPOSA contains information about recent developments at European level, including the proposed legislation on CROSS-BORDER HEALTH CARE and on MEDICINAL PRODUCT SAFETY.

Please tell us your ideas and needs and we will try our very best to support you.

Best wishes to all for a very HAPPY NEW YEAR.

Gerald Fischer
President PHA Europe

Contents

AUSTRIA

Christmas calender in Vienna

For 24 days in the Vienna city center a “Christmas calender” is projected on one of the city’s most famous historical coffee shops: the Landtmann Cafe. The Christmas calender will give great visibility to PH as it features the web address of Austria’s PH patient association, www.lungenhochdruck.at. Every day there will be a different painting in the calender “window” (one for each day of the Advent).

The calender will appear in the local newspaper Oesterreich and will be seen before the evening movies in the TV stations from Seven One Media (Pro Sieben, RTL, Sat 1, Kabel 1 & Puls4). Several times per day there will be 10 second spots about the opening of the window as well. Every tourist bus visiting “Christmas in Vienna” will pass there as well as many cars. The Landtmann Cafe is located opposite the Mayor’s Residence, and famous Christmas Market, and next to the Burgtheater (Royal Theatre). This calendar is famous in Vienna and everybody will be curious to see for which charity it will be this year. We are sure to get on top of this many PR articles and possibilities for talk shows.

Leading Ladies Award to Maleen Fischer

Maleen Fischer, Gerry’s daughter, recently won a Leading Ladies Award for her social engagement concerning her fight against PH conferred from the magazine “Madonna”. On the photo you can see Maleen (2nd from right) with the celebrity Sylvie van der Vaart, model, actress and TV presenter, who also received the award.

Maleen Fischer (2nd from right) with celebrity Sylvie van der Vaart at the Leading Ladies Award ceremony

Patient meeting

Over 75 patients from all over Austria attended our PH patient meeting in Vienna at Gartenhotel Altmannsdorf. This is the largest gathering organized so far by our association and we are very happy with the exceptional response.

Gerald Fischer with Prof. Andrea Olschewski at the patient meeting

Prof. Irene Lang, PH specialist from the Vienna General Hospital (AKH) provided a very interesting update on new therapies.

Prof. Andrea Olschewski, Director of the Ludwig Boltzmann Institute in Graz, spoke about her work within the Research Institute.

Dr. Doris Haider, a pharmacist, spoke about the management of PH treatments in everyday life.

The importance of learning how to breathe correctly and how to tackle stress and anxiety were addressed in two workshops on Qigong and meditation.

Eva Grassmugg,
Selbsthilfegruppe
Lungenhochdruck

News from European PH patient associations

BELGIUM - VZW

Patient meeting

On the 26th of November we held our annual meeting with Prof. Marion Delcroix (PH specialist at the Uz Leuven/Gasthuisberg), patients and PH Belgium.

Future plans 2011

In 2011 we are celebrating our 10 years of PH Belgium and on the 4th of December we are going to start preparing our festival program. On the 22nd of January we will have a New Year's meeting for patients and the organisation. Projects for 2011 include: an international nursing day (12th of May), a meeting for new patients, a youth program, a family outing at the zoo and a cycling event. Like every year we also plan to hold a meeting between PH Belgium and the pharmaceutical industry.

Hendrik Ramaker
Patiëntenvereniging Pulmonale Hypertensie vzw

www.ph-vzw.be

BULGARIA

12th National Cardiology Congress

The 12th National Cardiology Congress was held between the 7th and 9th October in Albena. I was invited to participate at the Congress and to present our association and its activities.

Plovdiv Autumn Fair

The Plovdiv Fair took place between the 8th and 31st of October 2010. During the Fair the National Alliance of People with Rare Diseases organized a "Solidarity stand", at which we were also present with other charities. This initiative raised 11.500 euros.

PH treatment in Bulgaria

In Bulgaria the problem with treatment of PH patients has not yet been settled. The Bulgarian Health Ministry has not planned yet the PH drug allottment for 2011. Therefore at this moment we still do not know how many patients will actually get treatment next year...

New name

We have made re-registration of the Bulgarian Association and now its name is PHA Bulgaria.

Todor Mangarov, PHA Bulgaria

www.apph-bg.org

CZECH REPUBLIC

Podûbrady rehabilitation stay

The third Rehabilitation Stay for PH patients was held during the summer (1st-8th August) in Podûbrady. It was organized with the support of the Czech Government and pharmaceutical companies. Rehabilitation was the main part of the program. We also took walks, went swimming, attended the doctors' lectures, etc.

New member of Board

The Czech Association has a new member of the Board since September 2010, MU Dr. Pavel Jansa. Dr. Jansa works in the Centre for PH (Prague). He is coordinator and prominent specialist for PH. Among others he lectures about PH in the Czech Republic and around the world. Dr. Jansa helps our association and his support is very important for us.

Follow up on Barcelona PHA Europe Assembly

Josef Oškera and Jirí Buneš, Members of our Board, attended the PHA Europe General Assembly. We particularly welcome the idea of engaging in common legal action to ensure equal access to treatment for all PH patients in Europe, providing guidance and support to "new" and "younger" patient associations and securing funding to tackle the language problem and promoting a Europe-wide awareness campaign. It is also very important to increase knowledge of the disease among primary care clinicians. We share the worries of other members with respect to finding new patients to increase membership (big problem), lack of funding, becoming financially independent from the pharmaceutcal industries. Getting the cooperation of the physicians and medical centres is also vital. English as a common PHA Europe working language is a big problem for our association.We would like to find volunteers who speak English well and also know something about PH.

Bulletin 2010

We are currently preparing a Bulletin for 2010. It will be a surprise for you. It should be printed in December 2010.

Katerina Novaková, Sdružení Pacientů s Plicní Hypertenzí

www.plicni-hypertenze.cz

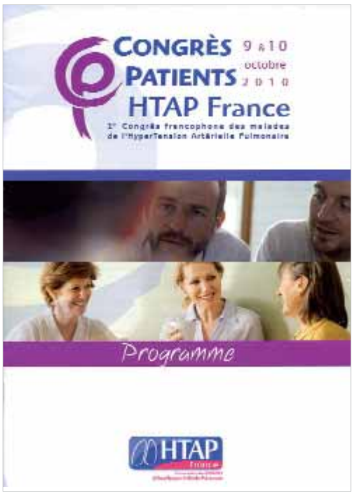
FRANCE

A pleins Poumons - sailing across the Atlantic for PH

A14 metre catamaran belonging to a close friend of HTAP France's President Sylvain Reydellet is taking part in ARC 2010, an annual transatlantic rally starting each November in Las Palmas, Gran Canaria. HTAP France is supporting this race together with PHA Europe. ARC is the largest transocean sailing event in the world and every year brings together over 200 yachts from all over the world. The destination is Rodney Bay in St. Lucia, an island in the Lesser Antilles. The 2800 nautical mile passage on the North East tradewind route takes on average between 14 and 21 days. The crew of six during this trip will be exploring the importance of breathing properly and of the relationship between man and nature.

First PH Patient Congress, Lyon

The first PH PATIENT CONGRESS organized by HTAP France was held in Lyon between the 8th and the 10th of October. About 180 persons attended the event, mostly patients and family members. The three-day program included scientific sessions held by world renowned PH specialists Prof. Gérald Simonneau and Prof. Marc Humbert (PH Centre in Clamart), as well as presentations and workshops on many different issues related to PH: treatment options, every day life with PH, family relations, pregnancy, children with PH, transplant and life after transplant, disability and administrative aid, etc.


CONGRÈS PATIENTS HTAP France
9 & 10 octobre 2010
1er Congrès francophone des malades de l'HyperTension Artérielle Pulmonaire
Programme
HTAP France

Mélanie Gallant Dewavrin, HTAP France

www.htapfrance.com

News from European PH patient associations

GERMANY

Annual Patient meeting in Frankfurt

Early diagnosis, targeted treatment and further research are the main factors in the fight against Pulmonary Hypertension (PH). This is the conclusion that the experts came to during the 13TH PATIENT MEETING of the German PH Association, held between 29th and 31st October in Frankfurt.

A highlight of this meeting was the 3,000 euro award for outstanding journalistic work in print media, radio or television on the subject of Pulmonary Hypertension given to journalist Bert Ostberg for a documentary on PH. The film shows a young PH patient at the THORAX CLINIC in Heidelberg in such bad condition to be confined to a wheelchair. Thanks to modern treatment and training at the rehabilitation clinic KING CHAIR HOSPITAL (Heidelberg), under the guidance of Prof. Dr. Ekkehard Grünig, this young patient now has considerably improved the quality of her life.

During the meeting, the 300 participants had the opportunity to learn about new therapies and innovative medicines and exchange experiences and information. Workshops such as "Influence of PH on a young couple" and "Life with a PH patient" allowed patients and relatives to share advice in dealing with affected spouses or family members. Expert speakers provided up to date information on new developments in diagnosis, therapy and treatment.

Topics discussed included: the importance of early diagnosis and treatment and the need for referral to expert centres for monitoring and follow ups. It was pointed out that GUIDELINES should never replace medical evaluation, and that each patient should be assessed individually. Speakers spoke of the possibility of further optimization of existing resources and the hope being raised by ongoing trials of combinations of drugs and novel therapeutic pathways. "Research is the best medicine" concluded Dr. Rosenkranz, one of the speakers.

left: Bert Osberg (at centre) with Phev President Bruno Kopp (1st from right)

right: Junior Fotball match with Bruno Kopp attending

For further details of meeting see:
www.phev.de/content/presse/prmittei.php

Junior football for PH

Bruno Kopp, Phev President, attended a Benefizfootball fundraising initiative (see photos). Together with other events 6.000 euros were raised to the Réné Baumgart Foundation.

Pulmonale Hypertonie e.v.

www.phev.de

IRELAND

PuckerUp4PH

The BLUE LIPS campaign continues to be a working project in Ireland. Our latest endeavours include a stand at the IRISH CARDIAC SOCIETY and the IRISH THORACIC SOCIETY, annual meetings. This was a great opportunity to speak to a variety of health care workers ranging from doctors to nurses and of course the general public. More activities are planned before we wrap up our efforts at the end of November.

I would like to wish all my friends in the PH groups around Europe a happy holiday from Ireland.

www.centreforlunghealth.com

ISRAEL

The Israel PH Association has been busy both planning and implementing new activities as well as maintaining existing ones.

The Blue Lips Campaign

Inspired by the global BLUE LIPS CAMPAIGN aimed at raising public awareness of PH around the globe, Israel, a country of just over 7 million people now places 7th in the list of countries aiming to collect 40,000 “blue lip” signatures. As of this writing nearly 1,600 blue lip signatures have been collected by PHA Israel at events in shopping centers, Tel Aviv’s famed Dizengoff Square and a major medical center. An event to collect blue lip signatures from students and staff at the TEL AVIV UNIVERSITY SCHOOL OF MEDICINE is underway as I write this report and it is quite probable that considerably more signatures were collected.

Patient Support

PHA ISRAEL continues to place major emphasis on supporting patients. One tangible expression of this commitment was the purchase of a sophisticated mobile oxygen system that will be lent to patients requiring such support while travelling or for other reasons. The Association continues its advocacy efforts in representing patients needs to official bodies and private companies. An ongoing effort is being made to reduce and if possible eliminate surcharges charged by national airlines for patients who must be accompanied by oxygen systems while travelling.

Support Groups

A monthly support group in which patients discuss diverse aspects of living with the disease has been underway in the center of the country for some time. These groups in the past have been facilitated by a professional and periodically also include social events: most recently a workshop on chocolate and jewellery making. Plans include a second support group in the northern part of the country to accommodate patients unable to travel to the center.

Support Group for parents of children with PH

Further expansion of support groups by PHA ISRAEL include plans to establish one geared for the parents and families of children with the illness. Assisting families of pediatric patients in their relations with the national insurance and health maintenance organizations is one aspect of the support that will be extended. Events focusing on strengthening the emotional and physical resources of these families and the building of a supportive community of families facing the challenges of caring for a PH patient are also foreseen.

Marathon Meeting of the Executive Board

Members of PHA Israel’s executive board vacated their work schedules and other commitments for a marathon set of strategy and planning meetings on November 17-18th. Under the chairmanship of the Association’s lay leader, Joni Berg, the board members and staff began their deliberations at mid-afternoon and continued into the evening followed by a working dinner. The meetings were conducted at a Jerusalem hotel where the board members who had come from outside the capital spent the night. Meetings resumed the next morning and continued through the early afternoon.

Annual Patients Conference

Among the decisions taken at the meeting was the scheduling of the annual patients conference in January. A subgroup of the board was charged with making the arrangements, scheduling the event and setting the program. While one focus of the patients conference will be on developments concerning treatment, sessions will also place emphasis on nutritional and fitness-related issues. The group dealing with the conference also decided that it will present a small gift from the Association to those attending the conference to foster the sense of belonging to a larger community of patients and caregivers. The duration and the venue of the conference may be extended this year possibly to include overnight arrangements at a hotel and social activities.

Symposium

The board also accepted a proposal to conduct a symposium aimed at:

1. Seeking to raise the awareness of PH among primary care physicians, nurses, therapists, and pharmacists.
2. The creation of an advisory committee of PH experts to coordinate policy and to provide guidance to the Association on medical matters.
3. Facilitate the establishment of a PH registry in Israel.

The symposium has been tentatively planned for late spring or the autumn of 2011. An organizational committee is under formation and key specialists have lent their names to the undertaking. We expect to announce the date and the program soon.

Yosef Gotlieb, PH Israel

ITALY – AIPI

Annual PH Conference, University of Bologna

The AIPI and AMIP associations, representating Italian PH Patients, were invited to attend a recent conference organized by the University of Bologna. This event featured updates on PH treatments, surgical options and research by prestigious PH specialists Nazzareno Galiè (University of Bologna) Gérald Simmoneau (France), Irene Lang (Austria) and surgeons Clemens Aigner (Austria) and Giorgio Arpesella (Italy). Pisana Ferrari, AIPI President, was asked to briefly address the audience.

New AIPI newsletters

Two new editions of AIPI*news*, Autumn and Winter, have recently been issued.

Marzia Predieri, AIPI Italy

www.aipiitalia.org

ITALY – AMIP

Echocardiogram equipment for Umberto I Hospital in Rome

Over the last few years AMIP has organized a number of fundraising events. With part of these funds AMIP has donated a VIVID S6 - echocardiogram equipment - to the Umberto I Hospital in Rome. AMIP members Vittorio and Laura, who lost two young children to PH, contributed very significantly to our fund-raising efforts. The medical staff at Umberto I Hospital recently invited PH patients and us to celebrate the new Echo equipment and organized a nice reception at the hospital. Prof. Fedele, Dr. Vizza and Dr. Badagliacca thanked us warmly for the the gift which they said will be invaluable to the hundreds of PH patients being treated in the PH unit.

above: the medical staff at Umberto I Hospital with the new Echo Equipment
right: Vittorio and Laura Vivenzio

Video interviews with patients

AMIP is now busy working on its most recent project, a documentary with video interviews of patients, due to be released at the beginning of the new year.

Luisa Sciacca della Scala, AMIP Italy

www.assoamip.net

NETHERLANDS

Recent activities and plans for 2011

PHA Nederland had several activities in the last part of the year. First of all, we organized a special meeting for patients who use Remodulin. Representatives of the companies distributing the drug and producing the pumps were present to speak about new developments and problems for the patients and to answer any questions. It was a very useful meeting and patients were able to talk about their personal experience with Remodulin. Two new editions of the PHA Nederland magazine Papillon have been issued and contain a lot of useful information for our patients. We have also started preparations of our yearly patient meeting in April next year. We really want to put together an interesting program with good speakers. Every year we close the meeting with something happy and cheerful to entertain the audience.

Ferdinand Bolsius, PHA Nederland

www.pha-nl.nl

NORWAY

PuckerUp4PH

The campaign finally reached the “land of the midnight sun” and flyers have been translated into Norwegian. I am a competitive backgammon player and have participated in several tournaments across the country. My fellow backgammon players willingly lent their lips to the Guinness record attempt. Pictures were taken of all participants and included in the article that has been featured on the main web page of the Norwegian backgammon association. It is probably safe to say that every serious backgammon player in Norway is now aware of PH! Bærum Basket, one of Norway’s best men’s basketball teams, has also been involved in the campaign. My son is the captain of the team and the players therefore had no hesitation in supporting the record attempt. We are still trying to persuade the coach to let the team play a game with blue lips as this would certainly attract the attention of both the audience and the press. However, he is hesitant as he is afraid that it will influence their playing performance.

Hall Skåra’s son (centre, with red tee shirt) with his basket ball team

Patient meeting

The Norwegian PH Association recently had its first meeting. It was difficult to find a time that fitted everyone’s schedules, so the first patient encounter was a telephone meeting! The agenda included reports from the PH conferences in LA and Barcelona, plans for making PH identity cards, PH pamphlets to be placed in hospitals, etc.

Glittleklinikken

The first PH patients have now attended a clinic specializing in training and diet tailored to lung patients. Although the main attendees of the clinic are COPD patients with care most probably geared towards this patient group, the initial impression is very good.

Hall Skåra, PHA Norway

www.pha-no.com

POLAND

Polish Europlan conference

One of our members attended the Europlan (European Project for Rare Diseases National Plans Development) meeting which was held in Cracow on the 22nd of November. Our association supports this project. At the conference doctors and members of the various associations of patients with rare diseases discussed implementation and monitoring of national plans. We hope that Europlan will help people with PH to have a better life and better health care.

Patient meeting

A meeting with patients and the organization took place in Warsaw on the 23rd of November. We discussed the future of the Polish PH Association. We talked about what we have already done and what we must do to be better. Our main goal is to increase knowledge about PH. We want to organize a PH Day. We know that it will be difficult, so as a first step we will join the “Day of the Heart”. This is a big event in Poland. Our future plans include improving the web site and posting more news, medical information and pictures and the organization of regional patient meetings.

Agnieszka Bartosiewicz, PHA Polska

www.tetniczenadcisnieniepłucne.pl

SLOVAKIA

Educational-reconditioning meeting of patients with PH

On 15th and 16th October 2010 an educational-reconditioning meeting was held at the Hotel Dixon in Banská Bystrica. It was attended by 33 members of the association. The meeting was preceded by a report from President Iveta Makovníková about the program and activities since the foundation of the association. Members were also informed of new challenges facing PH patients, which emerged from the conclusions of the PHA Europe meeting in Barcelona.

MUDr. Eva Goncalvesová, Head of the Transplant Department Núsch in Bratislava, spoke of the importance of diagnosing PH from the perspective of a doctor. MUDr. Luknár informed current members of the possibilities for diagnosis and treatment of PH. A short break was followed by a lecture by Ph Dr. Nôtová, psychologist, about the quality of life of patients with this disease. After dinner, patients had the opportunity of using the wellness center-massage, spa, walking, but most of them used their time to talk and to exchange experiences. The second day continued by breathing gymnastics and fitness exercises. At first the rehabilitation nurses explained the importance of exercises in PH and then continued with fitness exercises. Patients expressed great interest especially in exercise. Patients also had the opportunity to have an individual consultation with a psychologist.

The meeting was attended by patients who were already registered in the association as well as new patients. Patients were very happy and are already looking forward to the next meeting. Sponsor of the event was the AOP Orphan company.

Yveta Makovnikova,
Zdruzenie Pacientov s Plúcnou Hypertenziou

www.hypertenziapluc.szm.com

SLOVENIA

PH patients in Slovenia and Symposium on PH

A few months ago I made contact with Pisana Ferrari from PHA Europe and after the summer we met in Opicina, on the border between Northern Italy and Slovenia, to talk about the situation in my country and the possibility of setting up a patient group. At the moment I am trying to get people involved and it looks as though we may join a larger association for patients with heart and lung diseases.

Last year I was involved in the organization of a symposium on PH which was held in Ljubljana in November 2009. The symposium is witness to our desire to work together and share knowledge with the public about transplant and surgical options for thrombo-embolic PH. We hope that one day there will be more “trust” in these procedures and that they will be made available to all eligible patients. Three doctors from the Vienna University Hospital (AKH) were present: Dr. Peter Jaksch (pulmonologist), Dr. Irene Lang (cardiologist) and Dr. Walter Klepetko (thoracic surgeon). Other medical professionals present include Dr. Matjaž Turel, Dr. Barbara Salobir, Dr. Matevž Harlander, Dr. David Lestan and Dr. Tomaž Goslar, from the University Medical Center of Ljubljana. Each of them spoke about their involvement in thrombo-endoarterectomy (TEA) and transplant surgery. Two patients were also present, myself, having undergone TEA, and Alya Klara Ugovšek, who had lung tranplant. Many specialists in lung diseases from all over Slovenia attended. I really believe that there is too little knowledge of PH and we will try to do our best to raise awareness on this disease.

Klara Klančar

SPAIN

Europlan

A Conference of the European Project for Rare Disease National Plan Development (Europlan) was held in Burgos on the 6th of November. The conference was organized by FEDER, the Spanish Federation for Rare Diseases. This is the most important event of the year in Spain in the field of Rare Diseases. It brought together experts from different fields such as scientific societies, medical professionals, investigators, patient organizations and national health authorities, with the aim of reaching a consensus on a national Plan of Rare Diseases (for further details see page 9).

Cardiovascular Disease Congress

Over 3.500 cardiologists registered for the Cardiovascular Disease Congress SEC 2010 held in Valencia at the end of October. This Congress is organized by the Spanish Society of Cardiology and is considered to be the most important event in the cardiovascular field in Spain. The Spanish Association was present and the Congress provided the opportunity for networking and raising awareness on PH.

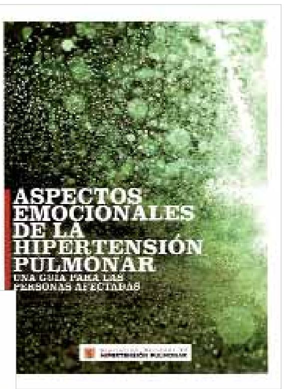
Santiago de Compostela pilgrimage

Santiago de Compostela is the capital of the autonomous community of Galicia, in Spain. The city's Cathedral is the destination today, as it has been throughout history, of the important 9th century medieval pilgrimage route, the Way of St. James. At the beginning of September a few members of the Spanish PH Association joined the Spanish Heart Foundation, for part of the 100 km journey leading to Santiago de Compostela (from the 7th to the 12th of September). Over 100 cardiac patients participated. The city is incredibly beautiful and it was a wonderful feeling to have made it there despite the limitations due to our disease!

Irene Delgado, President of the Spanish PH Association (first from right), with other association members, on the Way of St.James

New publications

Two new publications have recently been produced. The first is a patient guide and the other is a booklet on the psychological and emotional implications of living with PH.



ASPECTOS EMOCIONALES DE LA HIPERTENSIÓN PULMONAR
UNA GUÍA PARA LAS PERSONAS AFECTADAS

Aprendiendo a convivir con la
HIPERTENSIÓN PULMONAR

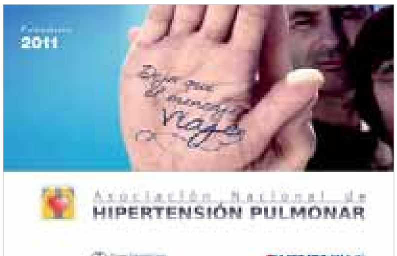
PH patient guide (right) and booklet on the emotional aspects of life with PH (left)

Christmas Lottery

A fundraising Christmas Lottery has been organized by the association with the aim of raising funds for its activities.

New Year calender

As in past years, the Spanish Association has just published a calender for 2011 which will be distributed to patients and their families as well as doctors and nurses from the various hospitals in Spain.



The December page of the calender features Rosa Maria Garcia, one of the two representatives of the Spanish Association, on PHA Europe

Board meeting

The Association's Board of Members met on the weekend of the 23rd and 24th of October to discuss the year's results and start planning activities for 2011.

Irene Delgado, Asociación Nacional de Hipertensión Pulmonar

SWITZERLAND - Schweitzer PH-Verein

Second PH children's meeting in Zurich

The first meeting for children with PH was held in 2009 in Horgen, and was extremely successful. We therefore decided to organize a second meeting, which took place on the 16th of October in Zurich at the Kispi (Kinderspital, Children's Hospital). Seven families attended. The meeting point was in the restaurant of the children's hospital at 10 o'clock in the morning. Here, the parents had the opportunity of listening to a very interesting lecture on PH and related issues by Dr. M. Fasnacht and were given the opportunity to ask questions and exchange experiences with the other parents. We wish to thank once again Dr. Fasnacht.

During the presentation our children were entertained by the hospital clown Dr. Kiko (from the Theodora Foundation - http://theodora.it/). The bright eyes of children during the performance are witness to how much they enjoyed themselves. After a good lunch at the Kispi restaurant we all went on a visit to the Zurich Zoo.

Annual meeting on oxygen therapy

On Saturday the 16th of October, in Olten, we held the annual meeting on oxygen therapy. The event's aim is to build a platform for information and knowledge exchange. This year's program also included a fascinating lecture on the subject: *How to become an "informed", competent patient*. Together with the social psychologist, Christina Calfetti, who is affected by a chronic disease herself, we addressed the question: *What can I do for myself?*

Various companies presented their products and services, and were available to answer questions. In this framework we also introduced our association to the companies.There was a nice lunch and sharing of common problems and experience.

Open day at the Kantonsspital St. Gallen Pulmonology

The Swiss PH Association was present with a booth at the inauguration of the renovated, expanded Pneumologieabteilung of the Kantonsspital St. Gallen on the 23rd of October. There are many new rooms, a clinic for rare lung diseases such as Pulmonary Hypertension, sarcoidosis, and many others.

Our information booth had many visitors. We had lively and interesting discussions amongst others with Councillor Ms. H. Hanselmann, hospital director Hr. Dr. D. Germann, Prof. Dr. M. Brutsche, chief physician Pulmonology/Interdisciplinary Center for Sleep Medicine and Dr. Nierhoff, LA Pneumology. Catering was provided and Barbara Burger, one of nurses, ensured that everything was perfect for us.

from left: Dr. D. Germann, Hospital Director, SPHV Vice President R. Emmenegger, Prof. M. Brutsche

SPHV on Facebook

Our association is now on the Facebook network with a page on "Pulmonary Hypertension in Switzerland". On this platform, we provide information about the various activities of the association and photos of the various events.

SPHV at meeting of the German PH Association

Eighteen SPHV members travelled to Frankfurt in October for the German Patient Association's Annual Meeting (29-31st October). The meeting was very interesting and we made many contacts with other patients and family members. Apart from the various lectures and workshops on the Saturday night there was also a very enjoyable cultural program with music.

Bruno Bosshard, SPHV

www.lungenhochdruck.ch

TURKEY

Turkish Cardiology Association Congress

PHA Turkey took part in the Annual Congress of the Turkish Cardiology Association held between the 21st and the 24th of October with a 9 square metre exibitor booth. This Congress is the biggest of its kind in Turkey and about 6.500 persons attended this year's edition. The Congress provided an important opportunity to interact with doctors, nurses and PH specialists. The association distributed brochures and other educational material to raise awareness of the organization.

Turkish Respiratory Society Congress

PHA Turkey also recently attended the Annual Congress of the Turkish Respiratory Society held in Antalya. One of the Members of the Board made a presentation and our honorary members Prof. Dr. J. Lewis Rubin and Prof. Dr. W. Klepetko gave support to our "PHA Turkey awareness power point slide". Both of them underlined the importance of cooperation between patient associations and the medical community and expressed satisfaction about the dialogue with PAH Turkey. It is really a great pleasure for PHA Turkey to have a sincere connection with Prof. Dr. J. Lewis Rubin and Prof. Dr. W. Klepetko.

PH Symposium

PHA Turkey took part in a 2-day Symposium held in Çesme. I was invited to hold the opening speech at the event and this was a great opportunity to give some information about the association, our aims, our past achievements and future plans, difficulties etc.

Patient helpline

PHA Turkey will be launching in the next few weeks (we are working on the technical details) a 24-hour helpline for patients. The helpline will provide medical information and psychological support.

Ümit Atli, Pulmoner Hipertansiyon Dernegi

www.pha-turkey.com

UNITED KINGDOM

PuckerUp4PH campaign now ending

We are indeed hoping to make an announcement about the PuckerUp4PH campaign in early December, but will not in time for this issue of Mariposa. We are planning on doing this for the Spring Issue of the EmPHAsis newsletter for the PHA-UK and will be sharing it with all the participating PH associations and groups at the same time also. Patient groups around Europe and the world are busy collecting the final lip prints. Blue kiss collecting events have been organized in Australia, Brazil, Mexico, Puerto Rico, Central America, Canada, the USA and many more.

Elizabeth Hinchey for PHA UK

Autumn issue of EmPHAsis

The autumn edition of PHA UK's newsletter is now out.

How to best make use of the PHA UK web site

PHA UK has recently issued an interesting and useful booklet which explains how to make the best use of PHA UK's web site. Very easy to understand, even for people who have no previous experience with computers.

www.phassociation.uk.com

News from PH patient associations around the world

LATIN AMERICA

Quarterly newsletter

The Summer 2010 edition of HAP en Noticias has recently been posted on the Latin America Society's web site. It contains reports on national associations' activities as well as patient stories and scientific articles. A delegation of the Latin America Society attended PHA USA's June Conference in Garden Grove. Some of the member associations took part in the PuckerUp4PH "Blue Lips campaign: Venezuela (with a 3 km marathon in July), Mexico, Puertorico, and the Spanish PH group in Miami. Many other associations have been busy in their own countries in providing support to patients and raising awareness. PHA Argentina, for example, held a meeting for patients and family members in September.

Blue Kiss collecting in a Puertorican school (right)

Event organized by PHA Argentina (below) and the Venezuelan association's July Marathon (bottom)

www.sociedadlatinahp.org

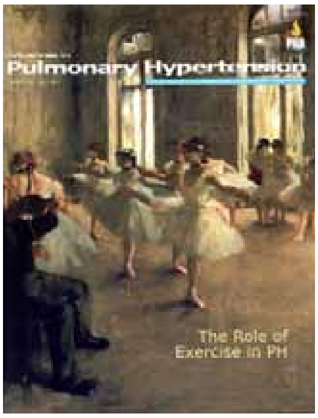
USA

PH Awareness month November 2010

Sixteen fundraising events took place during Awareness Month this November. Events organized included everything from a Casino night to a Masquerade Ball, a fun walk to a house party.

Advances in PH - Summer edition

The latest edition of Advances in Pulmonary Hypertension is about the role of exercise in PH. Topics discussed include: the role of pulmonary arterial pressure assessment during exercise, cardiopulmonary exercise testing in the evaluation of unexplained dyspnea, the therapeutic effects of exercise and rehabilitation in the PH Patient. Thinking has evolved considerably on the role of exercise in PH, explains the journal's Editor in chief Dr. Richard Channick. Exercise is no longer viewed as "contraindicated" and, in fact, data are emerging to suggest great benefits to pulmonary rehabilitation for patients.



The Winter 2010 edition of Advances in Pulmonary Hypertension will be dedicated to ethical considerations in PH and the Spring 2011 issue will deal with PH related to left heart disease.

Anyone can subscribe for free to Advances in Pulmonary Hypertension by contacting medical@phassociation.org. There is also a link to back issues online at www.PHAOnlineUniv.org/Journal

Tom Lantos Awards

PHA USA will be awarding grants of up to $5,000 to help raise awareness of PH or develop or expand services for patients. Applications for a Tom Lantos Innovation in Community Service Awards are being accepted until January 3, 2011. PHA South Africa was awarded a grant in 2010, which they used toward their first PH Retreat, the country's first meeting of patients, families, and PH specialists.

www.phassociation.org

PHA Europe in Stockholm for the ESC Annual Congress

The European Society of Cardiology (ESC) Annual Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines, from basic research to clinical practice. Approximately 27,000 people attended this year's ESC Congress which was held in Stockholm, Sweden, from the 28th of August through the 1st of September. PHA Europe was present with a booth and was represented by Pisana Ferrari, Vice President and Luisa Sciacca della Scala, Secretary. The growing interest in Pulmonary Hypertension from both the international medical and the scientific community is reflected by the increasing number of sessions that are dedicated to this disease. The final program for the 2010 Congress featured 2 symposia, 2 clinical seminars, 3 abstract sessions, 4 poster sessions and 6 mini-satellite symposia on Pulmonary Hypertension and related issues.

Networking about PH

The ESC Congress provided a wonderful opportunity for us to talk about PHA Europe, its aims and activities, with some of the top medical physicians, representatives of the pharmaceutical industry and other exhibitors. Luisa and I made some very interesting and useful contacts and distributed literally hundreds of the PHA Europe official journal, Mariposa News (both the spring and summer editions). Luisa and I took turns at the booth and in this way we were able to attend a couple of the sessions.

ESC Working group on Pulmonary Circulation

PHA Europe was invited to attend the meeting of the ESC Working Group on Pulmonary Circulation and Right Ventricular Function during which elections for the Working Group Nucleus 2010-2012 were held. Prof. Simon Gibbs (UK) was nominated as the new Chairman and Prof. Miguel Angel Gomez Sanchez (Spain) the Vice Chairman. In his thank you speech Prof. Gibbs, stressing the importance of establishing close links and working together with PHA Europe, put forth to the Nucleus members the idea of including a representative of the association on a permanent basis within the Working Group. We certainly look forward to any follow-up on this important idea.

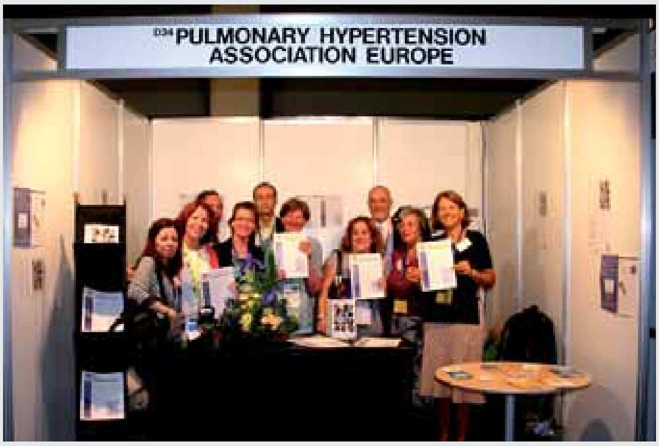
Meeting the Swedish PH group

Being in Stockholm for a few days also proved to be a great opportunity to catch up with Patrick Hassel who is a member of the Swedish Pulmonary Hypertension patient group. It was really nice to meet him at the Congress as we had been exchanging emails for some months. Patrick is the father of a young child with PH and works in the information technology business. He created the Swedish group's website (pah-sverige.se) and Facebook page. Luisa and I tried to talk Patrick into joining us in Barcelona for our General Assembly, but it was a bit too short notice for him and difficult to organize with a family and children. We sincerely hope he will come to next year's meeting. The Swedish PH group was only recently set up and has now joined a larger group, the Swedish Heart-Lung Association. On the very last day just before leaving, I managed to have lunch with Par Hommerberg, who works for the Heart-Lung Association (www.hjart-lung.se/). Par explained to me that the association has about 40,000 members with 160 associations represented. It is very influential at the national level, recognized by the government health authorities and is consulted on a regular basis. The idea of joining forces with a larger group is a wise choice for patient associations in countries with a relatively small population where it might otherwise prove to be difficult to have any significant impact on national policies. The larger group can provide some of the basic services and funding opportunities. Fortunately, patients with Pulmonary Hypertension in Sweden have free access to all of the treatment and surgery options, and there are excellent medical facilities. Patrick mentioned that there are perhaps a few too many "expert centres" considering the limited number of patients.

Luisa and I managed to take a few hours off to visit this most beautiful city, built on 14 islands connected by 57 bridges, with its wonderful nature, history and architecture. It was only a brief visit but enough to decide that we will definitely be coming back to see more of it!

Pisana Ferrari

PHA Europe Annual General Assembly and ERS Congress, Barcelona



PHA Europe booth at exibitor at ERS with delegates from Belgium, Israel, Netherlands, Italy and Spain

PHA EUROPE'S 2010 ANNUAL ASSEMBLY was held in Barcelona from the 18th to the 20th of September 2010 and had an exceptional turnout of 37 PH leaders from 18 European countries: Austria, Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Ireland, Israel, Italy, Netherlands, Norway, Poland, Slovakia, Spain, Sweden, Switzerland and Turkey. PHA Europe delegates from Greece and Portugal were unable to attend for health reasons. The meeting was organized in Barcelona coinciding with PHA Europe's presence at the European Respiratory Society's (ERS) Annual Congress. This Congress is the world's broadest respiratory medicine gathering, and it involves leading experts covering the entire spectrum of research and practice in respiratory medicine. Over 18,000 people attended this year's ERS Congress which included a number of sessions dedicated to Pulmonary Hypertension.

An interesting and wide ranging agenda

The two and a half day program of PHA Europe's Assembly included a report on this year's activities, presentations from the national patient associations, interactive sessions for sharing best practices and discussions about possible future strategies. Two prestigious and distinguished members of the medical community participated as guest speakers, Prof. Nazzareno Galiè, Head of the PH Unit at the University of Bologna Hospital in Italy, and Prof. Andrea Olschewski, Director of the Ludwig Boltzmann Institute in Graz, Austria, and provided very interesting updates on research, clinical practice and treatments. Rino Aldrighetti, Chairman of PHA USA, joined the group on Sunday and shared the history and experience of their association, from its initial setup "around a kitchen table" to its current activities and successes in terms of patient support, awareness raising, advocacy and lobbying for PH. Rino also came with us on a bus tour in Barcelona which provided the opportunity for delegates who had never been to this beautiful city to see some of the main monuments and sites. The Assembly ended with PHA Europe's first ever corporate meeting, held within the ERS Congress and attended by representatives from some of the main pharmaceutical companies involved in PH therapies. After this meeting, delegates were able to visit the PHA Europe booth, (see photo) and stroll around the exhibition.

Preparing for Barcelona

Needless to say, the PHA Europe meeting was preceded by months of careful planning, including an intense exchange of emails, arrangement of logistics and travel, and discussions about the program and speakers. PHA Europe President, Gerald Fischer, chose a wonderful venue in a small village by the sea, only a few kilometres away from the city. We did not have much free time during the assembly but at least the beach and the sea provided a lovely backdrop for our discussions. In advance of this meeting a questionnaire was sent out to all the members.

This questionnaire addressed issues such as:

- access to treatments and surgery;
- existence of expert medical centres;
- problems related to the running of a patient association;
- views about the role of PHA Europe;
- suggestions for common future strategies.

The answers obtained helped identify the key items to address in the agenda and provided the basis for our resultant discussions. We are very happy with the extremely high response rate: 100% of attendees.

Report on the year's activity

The very first item on the agenda was the report on this year's activity by Gerald Fischer. He started by making a point about the improved organisation of PHA Europe, with a full-time executive now working for PHA Europe and backup from the Austrian PH Association's Vienna office. He

PH brochures from Sweden, Netherlands, Germany, Poland, Spain and Turkey expressed great satisfaction about the increased networking and communication between the members, with regular exchange of emails, monthly updates and the introduction of the Mariposa journal. Since the beginning of the year, contacts were initiated and maintained with patient associations which had either been newly established, or not previously involved in PHA Europe: Bulgaria, Norway, Sweden, Slovakia, Ireland and the Netherlands. All of these associations have since expressed their desire to join PHA Europe and were present in Barcelona. PHA Europe attended at a number of important European scientific or industry events, such as the Rare Disease Day in Brussels, the Eurordis Conference on Rare Diseases in Krakow, the International Nurse Workshop in Berlin, the European Society of Cardiology (ESC) Congress in Stockholm, the PH Conference in Bologna, and many others. Some of these events provided excellent opportunities for speaking about PH. Mr. Fischer also stressed that another important achievement is represented by the exceptional turnout for the Barcelona meeting and the organization of the first PHA Europe corporate meeting.

Problems in managing a patient association

The second session was about achievements obtained and/or problems encountered at national level in running the association. The aim of this session was to share experiences among the members and to discuss ideas for events/activities, use of the web, newsletters and medical journals, attracting media interest, raising funds, relationships with medical centres, recruiting of volunteers, finding patients to increase membership, etc. The slides concerning achievements in the different countries showed an incredible variety of interesting, innovative and creative initiatives that ranged from publications to fundraising events to awareness campaigns. In addition, during the “problems” section of the discussion, some of the most common problems for a majority of patient associations were highlighted, namely finding patients in order to increase membership, finding people willing to work and commit themselves over time and funding. Involving physicians and medical centres could help solve the first problem. If doctors allowed patient representatives to be present in the hospitals or to leave their brochures and publications this would be an enormous contribution. Ideally physicians should encourage patients to join patient associations (as the ESC/ERS Guidelines suggest…) and even provide contact details. Websites, awareness campaigns and major events would also help. The lack of volunteers contributes to patient association volatility and is big problem which could be solved by hiring employed personnel. This is correlated to the issue of funding. If patient associations could count on a certain amount of funding over at least a three-year period, they would be able to consider employing someone, which would also improve future program planning. Unfortunately this is not often the case and patient associations tend to work on restricted funding, living with uncertainty about the future. As this issue is of utmost importance, it was decided to explore it further after the meeting and to collect ideas and suggestions from the members in order to produce a common paper.

Differences in access to treatment across Europe

The session dedicated to the current situation for PH patients in Europe was extremely enlightening. Despite considerable progress over the last 15-20 years in the diagnosis and treatment of PH, what emerged from the questionnaire and discussions is that the situation varies considerably from country to country. In some European countries patients do


View of the meeting room


Prof. Andrea Olshewski


Rino Aldrighetti, PHA USA President


Prof. Nazzareno Galiè with Gerald Fischer


from left: Prof. Horst and Prof. Andrea Olshewski, Gerald Fischer and Prof. Nazzareno Galiè

not have access to all of the EU approved drugs for PH: Bulgaria, Hungary, Poland and Slovakia. Even in the countries which are well organised from the point of view of PH patient management, there are still problems: in France there are problems with paediatric drugs, in Belgium and the UK there is an issue with Remodulin for "new" patients, in Germany Flolan is not available. Generally in these countries the bureaucratic procedures involved with access to drugs are very long. In other countries drugs are only available to patients who are in functional class III and IV (Poland). Also, some countries have no specialized PH medical centres (Bulgarian patients go to Thessaloniki, in Greece), whereas in others there are perhaps too many with respect to the population (Hungary, Poland) with a risk that some centres may not have enough patients or experience in patient management to really be "expert" centres. Many countries do not have transplant surgery facilities, thus requiring travel abroad for surgery (Bulgaria, Hungary and Slovakia). Some of these patients go to Austria where there is an excellent centre at the Vienna General Hospital (AKH). Finally, waiting lists are generally very long for transplants on account of shortage of organs, with only a few exceptions (i.e. Austria, where everyone is a donor by law).

Patient leaders' views on role of PHA Europe

The questionnaire had a section on patient leaders' views about PHA Europe, specifically on its current and future role. The feedback from the members was very positive. Most felt that things were being done well and in the general interest of the community, with everything being very "transparent" and a lot of information coming through. Many commented that having a person working full-time had made all the difference. "Central management" was considered to be a good solution to attract interest from areas such as: the EU, academia, R&D research, etc. There were so many suggestions on how to improve and expand PHA Europe activity that it was decided to put together a "Wish List" and take the matter up again. Ideas put forward included:

- the organization of a common European awareness campaign;
- being more present in EU conferences, meetings and seminars as speakers;
- providing funding of research grants to encourage and facilitate European academic research on PH;
- creating a special group for parents to children with PH;
- putting together a database with easily comparable information on reimbursement policies of different European countries;
- facilitating the new national associations that are just beginning their service on behalf of PH patients;
- improving communication and networking between the national associations in order to share more information and help the individual association promote the availability of treatments and public and professional awareness of the disease in their countries;
- taking all these problems to Brussels by lobbying MEPs and other EU institutions.

Language problems...

The problem of English being the working language for PHA Europe was one of the points raised in the questionnaire, and there was a long discussion about it. Language is a big issue for many members. The idea of having two persons from each association at meetings was originally put forward to allow members to bring along an English-speaking person. This appears to be working, and at the meeting in Barcellona all members had a friend or colleague translating simultaneously. However this is obviously not the same as listening in one's own language, as some parts may be missed, and it is also very tiring for the person translating. Most people seem to have fewer problems with written information. Some use online translating programmes such as Google, while others ask someone to translate. The language problem is unlikely to be solved very easily

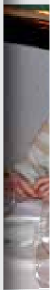
Natalia Maeva and Todor Mangarov (Bulgaria)

the Hotel Restaurant overlooking the beach

Iris Tal (Israel) and Maaike Atres (Netherlands)

Tapas and music in Barcelona

Agnieszka Bartowiecz and Marta Tomczyk (Poland)



and certainly not in the short term. Professional interpreters for meetings are too expensive, and there are too many languages involved. Translating written texts or at least providing abstracts in the different languages is a possibility to be further explored, especially considering cost. There is another language problem related to members not being able to understand each others' brochures, newsletters and websites. Mr. Fischer suggested and committed himself to obtaining funding to translate national web sites. This would already represent an enormous progress on the current situation.

Fundraising for PH

A highlight of the meeting was Mr. Fischer's brilliant presentation about fundraising for PH in Austria. Over the years he has organized extremely successful and profitable fundraising events, many of which involved thousands of participants and/or celebrities and politicians. Rock concerts at the Vienna Prater, auctions, museum openings, concerts by the Vienna Philharmonic orchestra, to name but a few… In his presentation he also provided many useful tips and insight on fundraising activity.

Making better use of internet and social networks

Patrick Fischer, PHA Europe President's son, also gave a very interesting presentation about the great potential represented by the internet, social networks and other new technologies. He explained how we could all take better advantage of the internet, i.e. sponsored ads on Google, which has special prices and even grants for charities. He also spoke about how easily we could set up Facebook profiles for our associations and use Twitter or YouTube. All these means can potentially reach thousands of people with very little effort. As an example, he showed a Facebook page called "Can this pickle get more fans that Twilight" (the profile picture being a… pickle!) which in a very few days managed to get almost 700,000 fans and thousands of messages posted! This is an absurd example of course, but it did help to bring the message home!

Conclusions

The meeting was generally felt to be very productive and useful, as reflected by the comments of the participants both during and after the meeting (some of the comments have been included at the end of this article), and most importantly the atmosphere was warm and friendly with the discussions being conducted in an open and constructive spirit. This allows us all to be very optimistic about the future of PHA Europe!

Pisana Ferrari

SOME OF OUR MEMBERS' SUGGESTIONS AND COMMENTS...

➠ *Dear Pisana, it was great opportunity and challenge for me and Todor to be in Barcelona. We learned a lot during this weekend. How is time for hard work for PHA Bulgaria! We must fight because we believe that all patients in Bulgaria with PH must have a normal life with all modern therapies. Compliments for the management team.*

Natalia Maeva, Bulgaria

➠ *The recent PHA Europe meeting in Barcelona was a very fruitful experience for me on behalf of PHA Ireland. It was great to see the level of commitment and enthusiasm demonstrated by all the representatives from the different countries. Ideas were shared and lessons learned from the experiences of other countries. I have personally joined Eurordis and accessed Orphanet since the meeting. I look forward to hearing how the proposed universal plan for increasing awareness of PH is going. I also hope with my colleagues in the PH unit in Dublin to encourage more participation from our patients in the future.*

Caitriona Minnock, Ireland

Tapas and music in Barcelona

from left: Pisana Ferrari (Italy), Hendrik Ramaker (Belgium) and Marta Tomczyk (Poland)

Gerald Fischer (Austria) and Kirsten Dahl (Sweden)

Rosa Maria Garcia (Spain) and Yosef Gotlieb (Israel)

Rosie and Luc Matthysen (Belgium)

Rino Aldrighetti (USA), Maaike Atres (Netherlands) and Guenther Thimm (Germany)

PHA Europe Annual General Assembly and ERS Congress, Barcelona

➼ *Dear all! Thank you so much for a great weekend in Barcelona! It was very inspirational and useful and besides my 20 copies of Mariposa, my "luggage" also contained a lot of ideas about how to move forward with the organization in Norway. Good luck with the PH work in your respective countries. Hope to see you all soon again!*

Hall Skåra, Norway

➼ *Dear friends, I really enjoyed the weekend in Barcelona. I obtained there much useful information, experiences and I met a lot of nice people. I am really looking forward to next meeting. Best regards*

Jiří Buneš, Czech Republic

➼ *Dear friends, we are very glad, that we could participate in meeting in Barcelona and meet all of you. It was a nice experience. We are looking forward to meeting you next year.*

Iveta and Martin, Slovakia

➼ *Dear Friends, all we can do is to echo and reiterate the previous mails. We found the weekend in Barcelona very useful; thank you for the very positive atmosphere, encouragement and good ideas which are solid basis to move forward and build the association at national levels. Hope to see you all soon. Kind regards,*

Eszter and Gergely, Hungary

➼ *Dr. Iris Tal and I represented the Israel Pulmonary Hypertension Association at the gathering. There, patients, caregivers and clinicians discussed treatment options, drug accessibility, standards of care, research horizons and general support for the victims of the illness. (…). Cordial relations transcending borders characterized the entire meeting. This "community of angels" is interfacing with other patients' rights and health advocacy groups across Europe, Israel, Turkey, North America, South America and elsewhere to further our common aims. Its growing successes represent the power of citizens' group to effect change.*

Yosef Gotlieb, PH Israel

➼ *Hello Gerry and Pisana, my feeling is that the PH meeting was a great sucesss. About 800 Mariposa News were handed out personally by me to people attending the ERS and visitors at the booth and it seems to me that interest about us is growing more and more among the scientific community. There is only one thing that I'd like to bring to your attention. As people were passing by our booth, our Mariposa didn't attract them as much as I think it should. The first aim of advertising is to attract the attention of prospective "customers". It is hard to realize what it concerns, since the title tells about "pulmonary hypertension" only in the third line. I do believe we should emphasize the disease more, maybe writing its name on top of "Mariposa News". Not too many relate the title to a butterfly and even fewer know that a butterfly is our PHA Europe logo. A drawing of Europe on the front page showing all the PH national member associations with their flag printed would be also be a very nice idea. Most of the material was handed out at several PH sessions always and unbelievably crowded. I would like to thank you for having arranged everything so smoothly and I wish you all my best*

Marzia Predieri, AIPI, Italy

➼ *I was very much impressed by Gerry's presentation about fundraising: it confirmed that it is possible to reach incredible results and that HE is able to involve all sorts of people, VIPs, artists, politicians etc in his "mission" against PH. While I was listening, I was thinking: if he can do this, why shouldn't we? He gave us good ideas on how to approach public relations and advertising companies and ask for help and even free advice. On the other hand, we all are aware that many of us lack Gerry's abilities. That's no reason to be discouraged. Shall we ever reach his results? Perhaps, it is possible and we are going to do our best to do so. Anyhow, in the meantime, everybody can go very far step by little step, beginning from one's small*

Martin Makovnikov and Yveta Makovnikova (Slovakia)

Rosa Maria Garcia and Irene Delgado (Spain)

Hall and Carol Skåra (Norway)

Josef Oškera and Jiří Buneš (Czech Repubblic)

Umit Atli and Ebru Arisoy (Turkey)

enf

circle of friends, colleagues, our chilren's school, our local church or sports group, to name but a few. Not having Gerry's gift for fundraising is no excuse! In a couple of years our association was able to finance two ambitious projects, thanks to this "nr.2 method": a 3 year grant to a doctor in a Childen's hospital (63.000 euros) and a new, up to date, echo machinery for Rome specialized centre (80.000 euros)

As Gerry was saying, it is important to know exactly what we need and build a clear project around it. The battle against a rare and severe disease like PH gives us the strength and power of persuasion to convince many, many people to give us their "little" help. It is interesting to describe the beginning of the intense and successful fundraising activity of our Board member Vittorio Vivenzio. It all started with a letter to the parents of their little boy Federico's kindergarten friends that Sister Melisa, their teacher, wrote. In very simple and touching words she invited to join and try to do something useful for other children affected by the illness that had taken away their little friend. What could be done? This was the important question. Here the help of our patients' association was fundamental. We conctaced Dr. Parisi, the doctor that had fought so strenously for Federico's health. During the years he had shown great competence and humanity. We also asked the opinion of the doctors of our Scientific Committee. It was finally decided to pay for a 3 years scholarship of research on PH. We took the right steps with the Bambin Gesù Childrens' Hospital in Rome, reached an agreement and, finally, having built a precise project, launched our fundraising campaign. From that little group of 4 year old children and their parents an incredible "chain" was originated. Vittorio and Laura, his wife, were offered to take part in a great number of small events: parish or school festivities, village fairs and so on. They gave interviews on local and national press and were invited to TV programs to tell their story. We discovered that everyone has a friend who has a friend that can help! Many shops in their neighbourhood offered to keep a box to collect the little donations their clients would leave. Transparency was essential to give us credibility. We kept accounts and sent receiptss for every cent we got while the list of donors with the amount of the donations was kept up-dated on a dedicated web site. Donors knew exactly where their money was going and how much was still necessary to reach the final goal. Many people organized something to collect more and donate again: a poker tournament among colleagues, a raffle, a charity dinner and many more.All this is to demonstrate that WE ALL CAN MAKE IT using the tools we have!

Luisa Bonelli, AMIP, Italy

➼ *Two of our members were at the PHA Europe meeting in Barcelona in September. It was a really nice and successful meeting. We could see that people in different country have the same problems with PH. We now know that we can do more, help more, be stronger in our fight for a better future for people with PH in Poland!*

Agnieszka Bartosiewicz, PHA Polska

➼ *The PHA Europe Annual General Assembly was a thrill for me to attend. I remember just a few years ago that this confederation was just an idea. Now- in Castelldefels, a beautiful beach suburb of Barcelona - it is clear how far that idea has come. Representatives from PH associations in 18 countries were meeting to discuss ways they can better work together and help each other grow. Many of the leaders, including PHA Europe's President, Gerry Fischer, and Vice-President, Pisana Ferrari and Melanie Gallant-Dewarin are old friends who have attended PHA Conferences and who we've worked with on many projects. I was honored to be invited to give a presentation about PHA in the U.S. As I spoke and heard the questions during and after, it was clear that, while we may speak different languages and live in different places our cause is the same…and that the cooperative spirit and common purpose that has made progress possible and rapid in the U.S. is the backbone of growth in Europe, as well. We look forward to our continuing and growing partnership.*

Rino Aldrighetti, USA

of the evening on the beach

Ferdinand Bolsius (Netherlands)
and Caitriona Minnock (Ireland)

Eszter Csabuda and Gergely Meszaros (Hungary)

Mélanie Gallant Dewavrin (France),
Agnieszka Bartowiecz
and Marta Tomczyk (Poland)

Patrick Fischer (Austria)
and Hendrik Ramaker (Belgium)

PHA Europe corporate meeting

PHA Europe at ESC Educational Course, Sophia Antipolis

The European Society of Cardiology (ESC) held its 2010 Educational Course on Pulmonary Hypertension (PH) on 15-16-17th October in Sophia Antipolis, France. The course is organized by the ESC Working Group on Pulmonary Circulation and Right Ventricular Function with its target audience largely cardiologists, pulmonologists and other specialists involved in PH care. This course consistently draws a very high number of participants. The 2009 edition represented a landmark event in that for the first time representatives of regulatory authorities, industry and patients were invited to present their perspectives. The G4, as it was called last year, has now become the G5, with representatives of the nursing profession being invited to attend and present in the 2010 edition.

Last year the ESC Course addressed the issue of "Gaps in evidence in the ESC Guidelines on PH" (see Mariposa news Spring 2010), and Pisana Ferrari was invited to attend and present the patient point of view. This year the topic chosen was "Registries, Trials and Annual G5 meeting," and PHA Europe President, Gerald Fischer, was invited to speak about "Patient expectations".

The agenda of the meeting was extremely interesting and comprehensive, including very qualified and distinguished speakers from the medical and scientific fields, as well as from industry and the regulatory authorities. The first two sessions were dedicated to Registries in PH and ongoing Phase III trials. The last session was the Annual G5 meeting, and its objective was to hear from all the stakeholders present their views. The following is a brief summary of the G5 meeting.

Nurses

The first speaker was Wendy Gin-Sing, a close collaborator of Prof. Simon Gibbs at the Hammersmith Hospital (UK). Mrs. Gin-Sing spoke about the role of the nurse in patient information and education. Nurses have a holistic approach to health care, and nurses play a vital role in PAH patient management. Over time, a strong therapeutic relationship is established between nurses and patients especially with chronic diseases. Patients tend to feel more at ease speaking with nurses than with physicians, especially about life-style related issues. Mrs. Gin-Sing stressed the vital importance of patient education and its advantages in terms of improved patient autonomy, drug compliance, management of daily life and outcome. Nurses at Hammersmith are very much involved in patient education in various ways including training sessions to manage therapies, life-style advice, hand books, etc. The nurses also collaborate closely with PHA UK (the UK patient association) who are very active in providing invaluable patient support through its website, help-lines, newsletters, conferences, patient weekends, awareness campaigns and patient advocacy initiatives.

Industry

The second point on the agenda was the industry perspective with six speakers from top pharmaceutical companies involved in PAH care: Actelion, Bayer, Eli Lilly, GlaxoSmithKline, Pfizer and Lung RX.

Mr. Christophe Giot spoke on behalf of Actelion about the possibility of developing a new end point for clinical trials. He said the 6 minute walking test (6MWT) is a good end point, but it is influenced by age and condition of the patient and could therefore give a distorted picture. Functional class (FC) is a "crude" variable and the time to clinical worsening (TTCW) is interesting for populations but not for individual patients. The aim should be to identify an end point closer to the clinical reality of patient management, which would increase the level of detail and allow for comparative trials. The ideal endpoint should be accurate, appropriate, form the basis of patient management and be a surrogate for survival. Christophe Giot suggests a coordinated effort between PAH experts, industry and the regulatory authorities in order to address this important issue.

Dr. Silvia Nikko (Bayer Shering) spoke about the challenges related to conducting clinical trials. Clinical development at the moment is saturated, and it is necessary to provide new *stimuli* to physicians as they are ultimately the ones who decide which trials to conduct and who encourage patients to take part. Patients are less willing to enter trials and are reluctant to be on placebo. Doctors are also reluctant to put patients on palcebo. It is important that physicians work together with patients and get their feedback. Recruiting is therefore major issue. Developing countries are a possibility, and it is vital to train investigators in these countries to conduct the trials with high ethical standards. Dr. Nikko concluded by thanking the organizers for bringing all of the parties involved in PAH care together in this meeting and stressed the importance for industry to build good and trusting relationships with physicians and other stakeholders.

Mr. Lucio Varanese from Lilly started his presentation by saying that PAH is nowadays a very "crowded" therapeutic area. The tendency in recent years has been for pharmaceutical companies to increasingly move from the "blockbusters" to "nichebusters" and this is the case for PAH. He spoke about company projects for the coming year: ongoing trials (Ambition and others), new indications/extensions, and studies in outcomes for specific patient populations. Lilly is also supporting registries (comparing ERA's) and external research (investigator initiated trials) as well as medical societies and patient associations.

Dr. Vignesh Rajah presented on behalf of GSK. He explained some of the broader challenges facing the industry: fewer drug approvals, plateau in patient outcomes, fragmented global research, high regulatory expectations, society's ability to pay for innovation and addressing diseases in developing countries. The new approach is about shared goals with regulatory, physicians and patients. GSK's commitment is strong, with its involvement in trials and its support for educational meetings. The key for the future is partnership: with academia, companies, foundations, charities. And the aim is not just "me too" drugs.

Mr. Colin Ewan represented Pfizer. According to Mr. Ewan despite progress mortality is still very high in PAH and this represents an "unmet need". Conducting clinical trials is increasingly challenging. It is vital to support earlier diagnosis and treatment, to have a rapid evolution in treatment algorithms for optimal drug choice and to explore new and innovative treatments. Pfizer is involved in numerous studies, including in the paediatrics area, and is looking into the next generation of PDE5 inhibitors as well as other potential novel targets for the future.

The last speaker was Dr. Gene Sullivan, Chief Medical Officer from Lung RX. His talk was about GOOD CLINICAL PRACTICE (GCP). GCP in Dr. Sullivan's view is extremely important: it protects patients' safety, promotes the validity of data, favours appropriate conclusions/extrapolations and finally promotes confidence in the decision making of regulatory bodies. Why is GCP all the more necessary now? It is important due to evolving experience and sophistication, together with the increasing number of large, multicenter, multinational studies. Applying GCP means: prompt data entry, early detection of adverse effects, drug accountability (where is the drug? i.e. thalidomide case…), real time identification of protocol implementation (i.e. failure to detect a problem can affect the outcome of a study). Delay increases the risk of error and decreases the ability to respond to queries.

Physicians

Prof. Gerald Simonneau, head of the PAH UNIT in Clamart, France, provided the "vision of the physicians". In his extremely interesting presentation Prof. Simonneau looked back on the progress achieved in PAH care in the last 15 years, from the first pivotal studies to the current situation with eight approved drugs, together with increased quality of life and survival for patients. Comparing results from the old studies and the more recent studies, he has observed that using the 6 minute walking test (6MWT) as an end point in the old studies would result in improvements of + 50 metres, whereas in the recent studies the increase is between 1-28 metres (mild…). Why is this the case? Could it be that the drugs are less effective/not effective? For some drugs yes, but mostly the population has changed. The studies with novel therapies are conducted on patients on top of other treatments as it is no longer feasible/ethical to use naïve patients as in the past. The exercise capacity of patients in recent studies may be reduced by de-conditioning (they have been ill longer). The 6MWT is now showing important limitations as an end point. It will be necessary to adapt the design of clinical trials.

Another issue is time to clinical worsening (TTCW). At the Dana Point meeting in 2008 a consensus was reached, and the new definition is more precise. It includes disease progression, change in functional class, etc. TTCW is a good end point for FC II but for FC III/IV it is necessary to demonstrate that the new drugs can actually improve patients (6MWT, hemodynamics, QOL combined end point). In an EMA concept paper about clinical trials on PAH there are 8 studies, half of which have 6MWT as end point and the other half TTCW. In future we will also need clinical trials with a longer duration.

As far as basic research is concerned, we need to test innovative compounds but not on the basis of monocrotaline rats. In vitro, the tissue of transplanted patients should be used.

Finally, initial development of drugs should provide safety and efficacy in patients who failed on prostacyclin and who are not eligible for transplant.

Regulatory authorities

European Medicines Agency (EMA)

The EMA regulatory authority was represented by Dr. Amani Al Gazayerly from the EUROPEAN MEDICINES AGENCY (EMA). Dr. Al Gazayerly reminded the audience that the EMA procedure for the approval of new drugs involves one application, one evaluation and one rapid EU wide authorization. Within the EMA a number of committees examine the various files: CHMP (HUMAN MEDICINAL PRODUCTS), PDCO (PAEDIATRICS), COMP (ORPHAN DRUGS) and other bodies involved include the SAWP (SCIENTIFIC ADVICE WORKING GROUP) and the CVWP (CARDIO-VASCULAR WORKING GROUP). Dr. Al Gazayerly explained that EMA has a very conservative approach, not innovative. In EMA's view, the main problems related to randomized controlled studies (RCT's) for PAH are: short duration (12 weeks), the efficacy of the 6MWT as an end point, the exclusion of unstable patients and patients in early phases of the disease. If the latter patients were put on a registry EMA could monitor them in a longer term situation. On the subject of registries Dr. Al Gazayerly said that there is an issue of whether these should be product or disease-specific. EMA data are product specific. Disease specific registries capture more events.

Currently in Europe registries available include the ORPHANET DATABASE, which has NATIONAL INSTITUTE FOR HEALTH (NIH) PAH survival information from 1984-1985 followed through to 1988. When the application for the Revatio

extension to FC II was filed, data from the French National Registry was provided. For the paediatrics indication, Tracleer data from four different registries was provided to examine the long term safety.
EMA would favour the setting up of a consolidated European wide registry by disease with input from patient associations, health care providers and health authorities.

Food and Drug Administration (FDA), USA

Mr. Satjit Brar from the US FDA has been involved in setting up an adult PAH trial database since 2008. The aim of this project is to improve the trial design of current adult PAH development programs. The current typical trial design may not suffice to meet the public health need: patients are in FC II or III, there are different aetiologies, the end points are the 6MWT, TTCW, change in FC. Also, most of the trials are "me too" drug trials. FDA understands the challenges involved: few patients, heterogeneous populations, uncertainties in the 6MWT. Having heterogeneous populations means that, for example, connective tissue disease and idiopathic PAH, which have very different outcomes, are practically two different diseases. There is talk of further breakdown in labels about different aetiologies. Another worry is the ethical issue about using naïve patients. However, the efficacy of new therapies needs to be demonstrated in combination with approved PAH drugs. The 6MWT as a primary end point needs to be further analysed. The effect sizes are small, and over time it decreases. There is less of an effect in the new studies with respect to the old. It is becoming more difficult for physicians to show efficacy.
Recent trials using TTCW, as well as the new publication by Dr. Valerie McLaughlin are very welcome. It includes as indicators of TTCW hospital stay, balloon atrial septostomy (BAS), functional class worsening, need for additional therapy, lung transplant, death. Hemodynamics are also very important and thus a threshold should be incorporated in the TTCW indicator. Cardiac function by imaging could also be added. Another major issue is that clinical progression and time course are not well characterized. With regard to bio-markers, there should be a serial measurement throughout the trial, not as a primary end point, but as a supportive end point to help understand what is happening. Treatment effects during inter-dose interval should also be measured to help gain better insight.
Registries will help identify the underlying factors for PH and achieve better trial design. Registries are already being conducted for safety, but they could tell more about patient outcomes in patient sub-groups and predictions of outcome short-term and long-term. Exploring registries could provide answers. To conclude, in future trials some features will need to change, and there is scope for refinement of current end points, especially TTCW, with more news about hemodynamics and bio-markers. It is important to maximise what we will learn from future trials and integrate it with current knowledge.

Patients' expectations

PHA Europe President Gerald Fischer's presentation opened with a summary of the most important issues for PH Patients: early suspicion of disease, early diagnosis, referral to expert centres, best possible information, best possible treatment (or combination of treatments), best possible surgery, involvement in all decisions regarding health care, and above all, finding a cure, i.e. the importance of funding for research.
Early suspicion and diagnosis could be achieved through awareness campaigns at general practitioners level, for pulmonologists and cardiologists or ads in medical magazines, symposia with the support of PH specialists and pharmaceutical companies aimed at education of general practitioners. In schools there could be screening (with a right heart echo) of children with excessive fatigue from running around or doing gym. Likewise screening of women during pregnancy or having recently given birth to a child with unexplained breathlessness could also be important. Screening of patients potentially at risk on account of associated conditions (congenital heart disease, scleroderma, HIV, etc.) could also be conducted. Statistically we have moved in the past 10 years to two doctors and two years from three doctors and three years to get a PH diagnosis, however this is still unsatisfactory. There are still cases of wrong diagnosis (asthma, other respiratory diseases or even anxiety, depression, etc.).
Once diagnosed, patients should be referred immediately to a centre of excellence. In the expert centres patients should be able to obtain (without cost) the best available treatment (not depending on NYHA functional class!)
Treatment options (single or combination) suggested by a centre of excellence should be accepted by every health insurance in every European country. To achieve this we need help from PH specialists to make clear guidelines and provide easily understandable information for doctors of health or social insurance departments. Good communication between the centres of excellence and the local centres, or the specialists treating patients during the rest of the year is vital.
Patients should have access to the best possible information about their disease. Patient associations can play a very

important role in this respect. If the centre of excellence has a special PH clinic day, it would be very helpful to allow representatives of the patient organizations to meet patients whilst they are waiting for a visit and allow for educational material to be distributed. PHA Europe wishes to establish a well-organized patient association in every European country.

Another very important point is patient involvement. Thanks to the internet, patients are more and more aware of possible treatments and should be involved in any decisions regarding treatment options. Patient meetings are becoming increasingly important in this respect. Quality of life is possibly more important than survival, and importantly, each patient has a different definition of his or her quality of life. Also, transplant should not always be the very last option.

Finding a cure: this is the most important expectation of our patients! Research is vital.

PHA Europe must work closely together with EURORDIS and ORPHANET at the EU level. With the support of a lobby agency in Brussels, it should inform political representatives in charge of health about PH and rare disease issues. The support of PH experts is necessary to inform PHA Europe about possible funds for research at the EU level and to inform the local PH patient association about possibilities of obtaining research funds in each country.

Pisana Ferrari

Update on PH treatments

At the time of going to print the most important news is the withdrawal of Thelin from the market.

Pfizer Inc. announced in a press release on the 10th of December that, “in the interest of patient safety, it is voluntarily withdrawing Thelin (sitaxentan) for the treatment of pulmonary arterial hypertension (PAH) in regions where it is approved (the European Union, Canada and Australia). In addition, Pfizer is discontinuing clinical studies of Thelin worldwide.

Pfizer’s decision was based on a review of emerging safety information from clinical trials and post-marketing reports. While liver toxicity is a known complication of the class of drugs to which Thelin belongs, a new potentially life-threatening idiosyncratic risk of liver injury with Thelin has been observed. Given the availability of alternate treatments, Pfizer has concluded that the overall benefit of Thelin no longer outweighs the risk in the general population of PAH patients. The Company has notified health authorities about this finding and its decision to voluntarily withdraw Thelin from the market and stop clinical studies.

(.......)

Pfizer recommends that no new patients be prescribed Thelin and that patients receiving Thelin be transitioned to appropriate alternate therapies as soon as safely possible according to best local practice. Patients taking Thelin or participating in Thelin studies are advised to consult with their health care professional as soon as possible. Patients should not stop taking Thelin until they speak to their health care professional.”

For further information, Pfizer suggests to contact the local Pfizer Country office (Pfizer country websites can be accessed at http://www.pfizer.com/general/global_sites.jsp).

Next PHAE newsletter

The Spring 2011 issue of the PHA Europe newsletter is due out in **April**. The first part of the new Mariposa will contain a report on the PHA EUROPE BREATH TAKING AWARENESS CAMPAIGN which will be organized around International RARE DISEASE DAY (28 February) in two major European cities, Brussels and Vienna. We would like to include reports and photos also of the local events being organized by the members and would be very grateful if you could send your contributions by **the end of March at latest**. The same applies for any contributions relating to other activities at national level. You may send these in your own language and we can provide for translation.

Another point on which we would appreciate your help is the distribution of Mariposa and building up of a mailing list. The newsletter will be available in PDF format and in a printed version. The PDF can be e-mailed, and the printed version can be posted either directly from Milan to your mailing list or sent to you for further distribution. Please advise. Many thanks in advance!

Update on cross-border health care

On the 27th of October the European Parliament Environment and Public Health Committee adopted a report on the draft Directive on “cross-border healthcare”. Adoption of the Directive in European Parliament plenary session is indicatively scheduled for 18 January 2011.

Background:
In June 2010 the European Health ministers reached an agreement on a draft directive on “cross-border healthcare” would allow patients to seek medical treatment outside their main country of residence (within the EU) and be reimbursed by their country “of affiliation”. We reported this in Mariposa News, summer 2010 edition.

The Council has now adopted its “first-reading” position on the draft directive (13 September 2010). The Council’s position acknowledges the case law established by the European Court of Justice on the patients’ rights in cross-border healthcare and seeks to balance this with the member states’ rights to organize their own healthcare systems.

The main provisions of the Council position are summarized in the official press release http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/116482.pdf

- patients will be allowed to receive healthcare in another member state and be reimbursed up to the level of reimbursement applicable for the same or similar treatment in their national health system;
- in case of overriding reasons of general interest (such as the risk of seriously undermining the financial balance of a social security system) a member state of affiliation may limit the application of the rules on reimbursement for cross-border healthcare;
- member states may manage the outgoing flows of patients also by asking a prior authorisation for certain healthcare (those which involve overnight hospital accommodation, require a highly specialised and cost-intensive medical infrastructure or which raise concerns with regard to the quality or safety of the care) or via the application of the “gatekeeping principle”, for example by the attending physician;
- member states of treatment will have to ensure, via national contact points, that patients from other EU countries receive on request information on safety and quality standards on their territory in order to enable patients to make an informed choice;
- the recognition of prescriptions issued in another member state is improved; as a general rule, if a product is authorised to be marketed on its territory, a member state must ensure that prescriptions issued for such a product in another member state can be dispensed in its territory in compliance with its national legislation;
- sales of medicinal products and medical devices via internet, long-term care services provided in residential homes and the access and allocation of organs for the purpose of transplantation fall outside the scope of the draft directive;
- concerning healthcare providers, the Council’s position seeks to ensure that patients looking for a healthcare in another member state will enjoy the quality and safety standards applicable in this country, independently of the type of provider;
- member states may adopt provisions aimed at ensuring that patients enjoy the same rights when receiving cross-border healthcare as they would have enjoyed if they had received healthcare in a comparable situation in the member state of affiliation.

The Council’s position was forwarded to the European Parliament for its “second reading”. On the 27th of October 2010 the draft report was adopted by 47 votes to 2 with 1 abstention by the EP Environment and Public Health Committee.

For further details see: http://www.europarl. europa.eu/sides/getDoc.do? pubRef=-//EP//TEXT+IM-PRESS+20101025 IPR90069+0+DOC+XML+V0//EN&language=EN)

French MEP Françoise Grossetête (European Peoples Party) who has acted as Parliament’s rapporteur on this directive defined the three main differences between the Council and European Parliament positions: prepayment, prior authorisation and rare diseases.

- On the first point, MEPs added a provision that Member States may offer their patients a voluntary system of prior notification, whereby, in return for such notification, the reimbursement would be made directly by the Member State to the hospital providing the treatment.
- On the issue of prior authorisation, the committee agrees with the principle that for hospital and certain forms of highly specialised care Member States may introduce a system requiring prior authorisation if the financial balance of the Member State’s social security system or the viability of the health system could otherwise be seriously undermined. MEPs also agree with the Council that the Member States, not the Commission, must decide which treat-

ments should require prior authorisation. They say that the prior authorisation requirement must not create an obstacle to the freedom of movement of patients. The committee also narrowed down the list of reasons for which a patient can be refused authorisation for cross-border treatment.

- On the last point, MEPs added *special rules for patients with rare diseases* (estimated in 25 million), saying that "patients affected or suspected to be affected by rare diseases have the right to access healthcare in another Member State and to receive reimbursement even if the diagnosis and/or treatment in question is not provided for by the legislation" of the home Member State. Such treatment shall, however, be subject to prior authorisation.

Adoption of the Directive in European Parliament plenary session is indicatively scheduled for 18 January 2011. PHA Europe will be monitoring developments closely.

For further details see: http://europa.eu/rapid/pressReleasesAction.do?reference=MEMO/08/473&type=HTML&aged=0&language=EN&guiLanguage=en

New European Medicines Agency (EMA) policy

On the 30th of November 2010 the European Medicines Agency adopted a series of new measures regarding conflicts of interest and access to documents related to medicines for human and veterinary use. The new policy introduces a more efficient and transparent process ensuring that scientific committee members and experts participating in the Agency's activities have no interests in industry which could affect their impartiality. It also gives wider access than ever before to documents held by the Agency, while it ensures that personal data and commercial confidential information remain adequately protected. The EMA's new policy responds to increasing public demand for more openness and transparency.

For further details see: http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2010/11/news_detail_001158.jsp&murl=menus/news_and_events/news_and_events.jsp&mid=WC0b01ac058004d5c1

European Union Committee of Experts on Rare Diseases 's first meeting

The newly formed European Union Committee of Experts on Rare Diseases (EUCERD) hels its first meeting on 9-10 December in Luxembourg. Rare disease experts Stakeholders in the field of rare diseases, including representatives from DG Sanco and DG Research funded projects, the rare disease patient organisations and the biopharmaceutical industry, welcomed the new EUCERD member representatives coming from each of the Member States. During the meeting the Members of the Bureau of the Committee were elected. Ségolène Aymé (Orphanet) was elected President of the Committee for a two-year term. The Bureau will have three Vice-presidents: Yann Le Cam (Eurordis), Kate Bushby (Treat-NMD) and Helena Kaariainen (National Institute for Health and Welfare Helsinki). The state of the play of the Europlan Project was presented. This included the national plans or strategies for rare diseases; guideline documents proposed for the national Europlan conferences; a report on the outcome of the Europlan national conferences in 2010; and the closing Europlan conference taking place in Rome, Italy during February 2011.

For further details see: http://www.orpha.net/actor/EuropaNews/2010/101215.html

Protecting patients: EU to upgrade medicine safety monitoring

An update of EU legislation on medicine safety was approved by the Council and endorsed by the European Parliament in Plenary session on the 22nd September. Patients will in future be better informed on how to use medicines, and enabled to report their adverse effects directly to national authorities. The EU and Member States will set up pharmacovigilance web sites to give information on medicinal products and their proven side effects. Medicines that need special monitoring after being placed on the market will be marked with a black symbol with the statement "This medicinal product is subject to additional monitoring", together with an explanatory sentence. The new EU pharmacovigilance legislation must be put into effect within 18 months of its publication in the EU Official Journal.

For further details see: http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+IMPRESS+20100921IPR83194+0+DOC+XML+V0//EN&language=EN

Patient engagement in Health Assessment Technology

On the 17th of November, EPPOSI, the European Platform for Patients' Organisations, Science and Industry*, organized a workshop bringing together experts from patients' associations, national and regional Health Technology Assessment (HTA)** agencies, EUnetHTA***, national health systems, public health and social science academics, clinicians and healthcare practitioners, and the pharmaceutical and biopharma industry with the aim of identifying the barriers to greater patient engagement in HTA. The full recommendations will be published in December and form the basis of a new thematic programme to be launched by EPPOSI in 2011 to help facilitate better HTA processes by all partners. *“It will seek to build multi-stakeholder innovative models for rational decision-making processes in the context of very diverse EU health systems with scarce health resources. The key will be to build a sustainable model which carries patients’ as well as public confidence,”* commented Jacqueline Bowman, EPPOSI’s Executive Director. To view the full workshop programme and for further information, see: www.epposi.org. Today HTA plays an important role in determining reimbursement decisions.

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* EPPOSI is an EU multi-stakeholder think tank on health policy. Based in Brussels, its main objective is the exchange of information to bridge the gap between innovation and public health.

** HEALTH TECHNOLOGY ASSESSMENT (HTA) is a multidisciplinary field of policy analysis that studies the medical, social, ethical, and economic implications of development, diffusion and use of health technology. It is increasingly playing a central role in how national healthcare priorities are set and service provision is delivered in most EU member states.

*** EUNETHTA Joint Action between the European Commission and EU Member States is a network of 34 government-appointed organisations from the EU Member States, accession countries and EEA, which runs from January 2010 to 2012. The aim is to help clarify what can be better achieved on HTA at EU level.

“Tweet” your Member of the European Parliament!

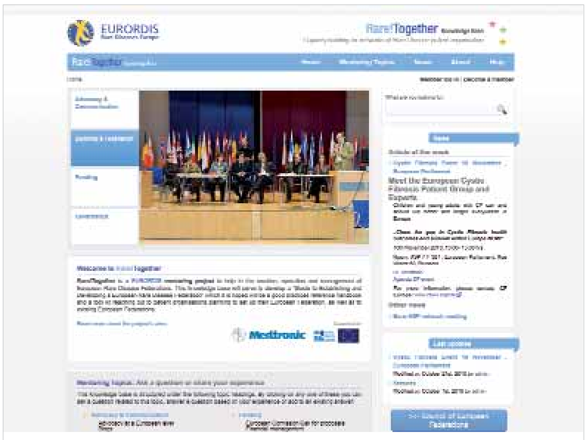
“Tweet your MEP!” is a recent and amusing initiative recently launched by TOUTE L’EUROPE, the best known Francophone website on European affairs. The idea behind it is to connect citizens to MEPs all over Europe. The web site (see http://www.tweetyourmep.eu/home/en) has a very attractive graphic layout with a map of Europe and includes a list of topics to choose from and a EU news section. Citizens are encouraged to try it out: *“Contact your MEP and have your say on the issues that matter to you!”* TWEET YOUR MEP is available in English, French, German and Dutch. It covers all 27 Member States. About 1/3 of MEPs have twitter accounts and are contactable via Tweet your MEP.

How do I know my country’s Members of the European Parliament?

We remind our members that they can very easily find: their country’s MEP’s by accessing the European Parliament web site at: www.europarl.europa.eu/members/public/geoSearch.do?language=EN and, more specifically, their country’s MEPs in the EP COMMITTEE ON THE ENVIRONMENT, PUBLIC HEALTH AND FOOD SAFETY at www.europarl.europa.eu/activities/committees/membersCom.do?language=EN&body=ENVI

Rare! Together

Rare! Together is a EURORDIS mentoring project to help in the creation, operation and management of EUROPEAN RARE DISEASE FEDERATIONS. The web site provides invaluable information, insight and advice on the following subjects:



- *Building a Federation:* membership, structure, registration, looking for other national groups, sharing experiences.
- *Advocacy and communication:* web sites, newsletters, blogs, mailing lists and online communities, the language problem (!), lobbying the EU.
- *Funding:* fundraising, transparency, EU Commission calls for proposals, support by commercial companies.
- *Governance:* Statutes, Board, General Assembly, employees and volunteers, good international practices.

The web site is interactive and it is possible to put forward questions on any of the above issues. An absolute must, there is a lot to learn, even for reasonably well “established” Federations such as our own! The web site has many examples of activities other Federations are involved in. Read about the CYSTIC FIBROSIS EVENT at the European Parliament, for example http://raretogether.eurordis.org/news/article-of-the-week/cystic-fibrosis-event-10-november-european-parliament/ There is a lot to learn here about getting MEPs on board and how far that can get you!

Lots more information at: http://raretogether.eurordis.org

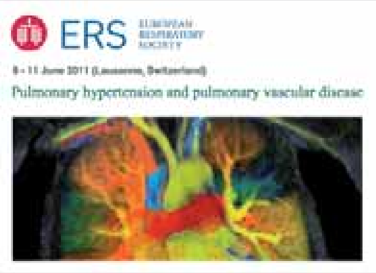
Pisana Ferrari

Upcoming events for 2011

28 February, Brussels, Belgium

RARE DISEASE DAY

February 28th 2011 will mark the Fourth International Rare Disease Day (RDD) coordinated by EURORDIS (European Rare Disease Organization) and organised with rare disease national alliances in 25 countries. On that day hundreds of patient organisations from more than 40 countries worldwide will be organising awareness-raising activities and converging around the slogan "Rare but Equal". PHA Europe will be holding its first Europe-wide "Breath Taking" Awareness Campaign on PH around RDD and this project has now received the patronage of EURORDIS.



9-11 June, Lausanne, Switzerland

ERS EDUCATIONAL COURSE OH PH

The course's target audience is respiratory clinicians, cardiology clinicians, trainees. The two day program will include lectures, workshops and case presentations. The course will be dealing with Pulmonary Hypertension and additionally with pulmonary embolic disease and the aim is that participants will emerge from the training with a better understanding of both conditions and a greater ability to diagnose, treat and manage them.

27-31 August, Paris, France

ESC ANNUAL CONGRESS

The European Society of Cardiology Annual Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines, from basic research to clinical practice. Around 29.000 persons attended the 2010 ESC Congress in Stockholm, Sweden. As in past years it is expected that there will a number of sessions dedicated to Pulmonary Hypertension. PHA Europe will be present as an exibitor with a booth.

24-28 September, Amsterdam, The Netherlands

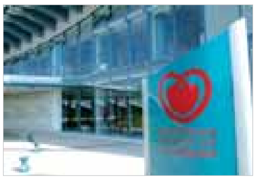
ERS ANNUAL CONGRESS

PHA Europe will be present with an exibitor booth also at the European Society for Respiratory Medicine's Annual Congress in Barcelona. This Congress is the world's broadest respiratory gathering. It involves not only leading experts in respiratory medicine, but also in other areas, covering the entire spectrum of research and practice in respiratory medicine. Over 18.000 persons attended the 2010 edition in Barcelona. As in past years there will be a number of sessions dedicated to Pulmonary Hypertension. PHA Europe will be present with a booth.

Sophia Antipolis, France (date and program not yet available)

ESC EDUCATIONAL COURSE: PULMONARY HYPERTENSION REGISTRIES, TRIALS AND ANNUAL G5 MEETING

This annual course on Pulmonary Hypertension is followed by a meeting of the stakeholders involved in PH management: physicians, nurses, patients, regulatory authorities and pharmaceutical industry.



2012

2012 AT A GLANCE

These events are held every two years are are scheduled for 2012:

- PHA USA International Conference, Orlando, Florida, June 22-24, 2012. Start planning!
- European Conference on Rare Diseases, Brussels, Belgium (date to be defined).

Interesting links and suggested reading

International Society for Heart and Lung Transplantation

The International Society for Heart and Lung Transplantation (ISHLT) is a professional organization dedicated to improving the care of patients with advanced heart or lung disease via research, education and advocacy. It was created in 1981 and has over 2500 members from over 45 countries, representing over 14 different disciplines. The web site has very interesting information on transplant related issues and provides useful links. The ISHLT has endorsed the 2009 ERS/ESC Guidelines on the diagnosis and treatment of Pulmonary Hypertension.
www.ishlt.org/

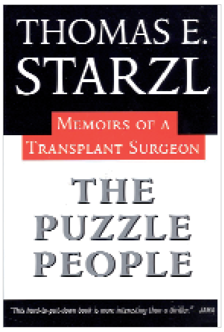
European Society for Organ Transplantation

The European Society for Organ Transplantation (ESOT) aims to become the umbrella organization for all European transplant activities. ESOT cooperates with many transplant organizations to structure and streamline these transplant activities in Europe. Several Organ Expert Sections within ESOT represent expert knowledge on the respective organs. ESOT trains and supports its members through an educational and basic science programme and an award and grant programme. The Thoracic Committee of ESOT was founded in 2006 as a separate section within ESOT to support and represent the Heart and Lung Transplant community in Europe. ESOT collaborates closely with the European Society for Heart and Lung Transplantation (see below).
www.esot.org

European Heart and Lung Transplant Federation

The European Heart and Lung Transplant Federation was formally established in 1994 by15 European National Heart-or Heart-Lung Transplant Associations. EHLF is a member of the European Patients Forum (EPF). One of the main activities of EHLF are the GAMES which are arranged bi-annually in one of the member countries and comprise of 20 track and field athletic events as well as tennis, table tennis, volleyball, badminton, cycling, golf and swimming. Since their start in 1989 the Games have become increasingly popular. The main purpose of our games is to illustrate the positive benefits of transplantation and to demonstrate to the general public that it is possible for transplant recipients to return to full and active lives, including physical acivity and sport.
www.ehlf.org

The puzzle people, memoirs of a transplant surgeon



Thomas E. Starzl was born in 1926 in Le Mars, Iowa. Retired from clinical and surgical service since 1991, Dr. Starzl is past Director of the University of Pittsburgh Medical Center's program named in his honor: the Thomas E. Starzl Transplantation Institute. For more than two decades, Dr. Starzl and his colleagues in Pittsburgh have expanded the frontiers of transplantation by pioneering such developments as cyclosporine and tacrolimus (formerly FK506), two key immunosuppressants, and the concepts of small-bowel and multi-organ transplantation. This book gives a great insight into the life and work of the people who made the developments in this field possible, their hard work in research and clinical practice, brilliant intuitions and courage to go ahead in the face of difficulties encountered on their way.
1992, University of Pittsburgh Press

Other information on transplant related issues:

- Eurotransplant Foundation: www.eurotransplant.nl
- Scandia Transplant: www.scandiatransplant.org
- European Transplant Coordinators Organization: www.etco.org
- European Society of Transplantation: www.esot.org

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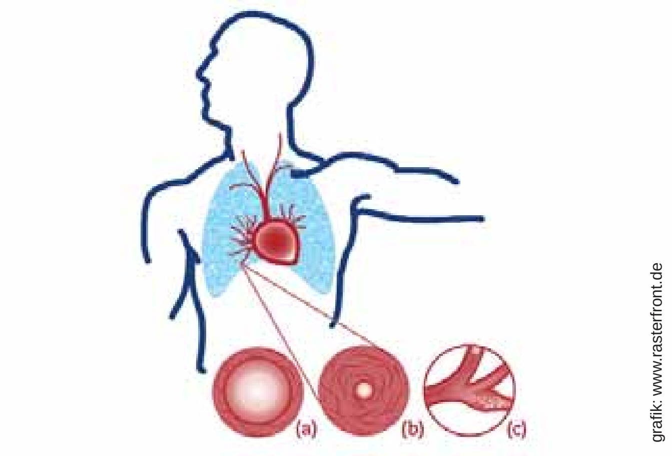
PHA EUROPE

AIMS OF PHA EUROPE

Pulmonary Hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European Pulmonary Hypertension patients.

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

In patients with Pulmonary Arterial Hypertension characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases up to 80% of these very small blood vessels are rendered non-functional. As a result the pressure in the pulmonary circulation rises well above normal and this places strain on the right side of the heart. This strain can cause the heart to enlarge and the patient may develop heart failure. This is a disease that can affect all ages and is more commonly seen in females. Pulmonary Arterial Hypertension has an estimated prevalence of about 50 per million population.



grafik: www.rasterfront.de

a. *Cross section of normal pulmonary artery*

b. *Reduced* lumen *of pulmonary vessels due to cell proliferation and remodelling in advanced Pulmonary Arterial Hypertension*

c. *Longitudinal section with pathological changes within the vessels proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs*

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade a number of evolving therapies that either use complex delivery systems such as 24-hour intravenous or subcutaneous drug infusion, drug inhalation and, more recently, oral medications, have transformed the outlook for PAH patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management. The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated the average life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies double lung, or in some cases, heart and lung transplantation may be appropriate.

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life threatening disease is still some way off, there is much to be optimistic about. There are an ever increasing number of therapies available for the effective treatment for Pulmonary Arterial Hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with Pulmonary Arterial Hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.